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Lisa Hilder

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THE EMOTIONAL AND INSTRUMENTAL EXPERIENCES OF CAREGIVERS OF SENILE DEMENTIA/ALZHEIMER TYPE PATIENTS

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

By
Lisa Hilder and Kerri Robertson
June 1993
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SENILE DEMENTIA/ALZHEIMER TYPE PATIENTS

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May 13, 1993
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ABSTRACT

This positivist descriptive study will address the question "What instrumental and emotional supports do caregivers of Senile Dementia/Alzheimer Type (SDAT) patients who score with symptoms of depression receive and need?" The hypotheses propose an inverse relationship between the dependent variable (caregiver scores on a depression inventory scale) and the independent variables (instrumental and emotional supports for caregivers). To test this, a convenience sample of 19 caregivers of SDAT patients were taken from the Inland Caregiver Resource Center (ICRC) client population in San Bernardino County. This list includes 10 caregivers who do score with symptoms of depression and 9 who do not. Letters requesting participation were sent, follow-up phone calls were made, and a 30-45 minute interview was conducted with the caregivers who consented to participate. Informed consents were obtained and a debriefing statement was given at the interview. The interview followed the format of a questionnaire which asked about the quantity and quality of the instrumental and emotional supports received and needed by caregivers. Bivariate analysis (crosstabs) were computed to find the relationship between the independent variables and the dependent variable. Qualitative data was obtained.
from the caregiver comments in the interview and analyzed by the technique of open-coding. The findings indicated that all caregivers need more instrumental support from the community, regardless of their depression score. The data regarding emotional needs suggests that caregivers experience a complex range of depression levels, hence a complex range of emotional needs, for which further research should be done.
INTRODUCTION

As the United States population ages, Senile Dementia -
Alzheimer's Type (SDAT) disease is an increasing problem in
our society. Due to society's lack of investment in the
elderly, caregivers of these victims have been generally
overlooked. Since most caregivers hold sole responsibility
for the victim and receive very little assistance in this
task, it is no wonder that social workers' experience
suggests that depression is quickly becoming a major
problem. (Fraser, 10/92)

Inland Caregiver Resource Center (ICRC) is currently
struggling with this issue of caregiver depression in their
daily caseloads of SDAT patient caregivers. ICRC services
are aimed at helping caregivers find resources, information,
and other various supports to assist them with their
caregiving responsibilities. As part of agency procedure,
caregivers are reassessed every six months and asked to fill
out a depression inventory questionnaire. Radloff and Teri
(1986) constructed this questionnaire to measure a person's
current emotional state. Scores can range from 0 to 60,
with higher scores indicating depressive symptomatology.
They found that a score of 16 or above indicated symptoms of
depression. In the last few years, the percentage of
caregivers scoring with symptoms of depression has
skyrocketed to 88 percent. The reason for this is unclear,
and thus, appropriate social work interventions have not yet been devised to help these caregivers. The purpose of this study has been to address this problem and answer the question, "What instrumental and emotional supports do caregivers of SDAT patients who score with symptoms of depression receive and need?" By discovering the answers to this question, this study will provide data from which program development and policy can be established to intervene appropriately with this growing population of caregivers with symptoms of depression.

To accomplish these objectives, this study utilizes the positivist paradigm. It is a descriptive study, in that it analyzes the quantitative and qualitative relationships between the independent and dependent variables. In particular, this study examines community resources and family/significant others support to determine if there is a correlation between symptoms of depression and these factors in caregivers.

This study focuses on a direct practice social work role. Specifically, the techniques, approaches, and services that ICRC social workers need to use in their intervention with caregivers displaying symptoms of depression.
LITERATURE REVIEW

It is thought that caregivers of SDAT patients experience a much higher level of stress and depression than the average population and yet have very little help from community, family, or significant others to deal with it. Pilisuk and Parks (1988) address this in their article "Caregiving: Where Families Need Help." They conservatively estimate that there are at least 6 million family caregivers of SDAT patients in the United States. Three-fourths of these caregivers live with the recipient and spend more than 6 hours a day assisting with personal hygiene, medication, household chores, transportation, shopping, getting the patient in and out of bed, etc. Most of the caregivers live in the community and rely on family, friends, and paid help to meet their needs, although less than 10% of caregivers report the use of formal services. This low utilization of services reflects the inadequacy of available services, not the wishes of caregivers. Caregivers report needing financial assistance, respite care, visiting nurses, supportive services, and family support. This study shows that caring for a loved one who is disintegrating daily causes chronic fatigue, anger, and depression in most cases.

Pruchno and Potashnik (1989) also address this issue in a study comparing 315 caregivers of patients with Alzheimers
disease or related disorders to general population norms in regards to self-reported physical and mental health. They discovered that caregivers score higher on depression scales, are more likely to use psychotropic drugs, have more symptoms of psychological distress, and express higher levels of negative affect than the comparison population group matched for age and gender. The majority of the caregivers in their study were unaware of the existing community supports and services available to them. Pruchno and Potashnik (1989) concluded that doctors need to be more aware of community services and supports and take the time to share and explain them to their patients.

In the process of developing and linking services for caregivers, it seems that the best way to find out what the caregiver needs is to ask them directly. Novak and Guest (1989) came to this conclusion in their study which examined the correlates of caregiver burden through degrees of feelings experienced and subjective perception of caregiving responsibilities. They found that caregivers of (SDAT) patients go through their own emotional decline. The practicality of this study for researchers is that professionals cannot assume in advance that they know what caregivers need. The best way to learn about their needs is to interview the caregiver(s) directly and develop appropriate services based on their responses.
It seems that the biggest need of caregivers is for social support. Zarit et. al. (1985) discovered this in their interviews with caregivers. They discovered that caregivers need the physical/instrumental component of social support, that is assistance with bathing, cleaning, cooking, etc. They also need the emotional component of social support that provides the feeling of support "gained from knowing that there is someone who understands the caregiver's experience and offers encouragement in times of difficulty." Caregivers tend to become quite isolated, receiving fewer visits from friends and going out less. This decrease in social contact may be the most stressful element of caregiving because it cuts the caregiver off from stabilizing normal interactions with other people. Research shows that caregivers who receive calls and visits from family members feel less burdened and depressed than those who do not. Granted, not all family contacts are positive, but as stated above, the best way to find out what supports will be most helpful for a caregiver is to ask the caregiver.

Once a caregiver is interviewed directly and their needs are outlined, it is often difficult to find resources that can be used to meet their needs on a short-term basis, let alone a long-term one. When this happens, it seems that the best way to help caregivers would be to teach them how
to help themselves whenever and wherever possible.

Gallagher (1985) and her team from the Palo Alto VA Medical Center conducted a study that tried out two psychoeducational approaches to coping with caregiving. They conducted two different classes for caregivers of frail elders (42% were dementia patients): the Life Satisfaction class and the Problem Solving class. Before, during, and after these classes, the caregivers were tested for changes in their level of knowledge, group cohesiveness, self-efficacy, and problem solving ability. It was found that improved outcome was related to improved self-efficacy.

Caregivers involved in a support group need more than just a discussion group. It is important to focus on the emotional experiences, but not at the expense of pragmatic means. Monahan, Greene, and Coleman (1992) organized a study based on a 14-month project of caregiver support group services. Thirty-four groups were held during the 14-month project. Each group, led by a social worker and a community health nurse, met weekly at the same time and site for two (2) hours over an eight (8) week period. Each of the sessions consisted of three (3) intervention components. The first component was a guided group discussion to assist caregivers in dealing with emotional and behavioral conflicts. The second was educational, to learn techniques and information useful to their role. The last component
was relaxation training to achieve a calmer frame of mind and decrease somatic and muscular pain. The authors found that several factors effected caregiver attendance. Beyond the influence of ethnicity and language as a most striking feature, the importance of a secondary caregiver was strongly associated with greater attendance. Interestingly, the second caregiver not only provided emotional support, but also provided effective respite care that allowed time for the primary caregiver to attend such meetings. Finally, Monahan, Greene, and Coleman (1992) proposed that a model which integrates formal services such as respite care, combined with a supportive system in which groups play an important role, is needed in encouraging and maintaining the informal system.

Caregiver involvement with an appropriate resource agency and support from family and significant others may decrease their level of burden and depression over time. On this issue, Friss and Winbush (1991) focus on understanding the changes in caregiver well-being. They found that caregivers with high baseline burden and depression levels can improve over time. They present strong evidence which identifies the mental health implications of caring for brain-impaired adults and that respite care alone is not enough. In this study, the longer a caregiver remained in the CRC (caregiver resource center) service system, the more
likely it was that they would actually use the support services and experience less depression and burden overall.

Caregivers of SDAT patients need the availability of respite services in maintaining their loved one in their own home. Spence and Miller (1986) examined the benefits of a family respite program while placing this report in the context of social policy, community values, and family expectations.

In responding to an outgrowth of interest expressed by the Alzheimer's Disease and Related Disorders Association, Incorporated (ADRDA) Westchester Chapter, the Administrative Director of the Nathan Miller Center for Nursing Care developed an apartment for respite care adjacent to their nursing facility. The purpose of the respite ranged from providing vacation time, relief and relaxation, to providing temporary arrangements while permanent arrangements for patient care were being made. Respite stays ranged from 4 to 30 days, with most in the 2 week category.

In evaluating the experience, several different criteria were identified to assure such a project's success. The client selection process must anticipate the ability of the guest to meet the expectations of placement. Therefore, assessment needs to include both the client's level of functioning with an accurate determination of the client's capability. In the family interview, items such as family
and individual history, level of cognitive ability, activities of daily living, and ability to ambulate safely must all be included.

In addition to the patient, it is important to recognize that the client served is also the caregiver. They are the focus of service delivery and must be involved, in that if issues are not recognized early on, chances are that placement will be considered unsatisfactory.

Lastly, attention must be given to the quality of staff providing services and the affordability of these services. The community must be involved since the program is meeting a genuine need of the community. Social policy and federal responsibility must be addressed in respect to the responsibility of maintaining these needed services. If families are to continue to play a significant role in caring for Alzheimer's patients, there will be a growing need for respite services. These services not only improve the quality of life for our elderly, frail, and chronically ill people, but they are cost effective and assist in delaying or preventing institutional care.

In reviewing these recent studies, it seems that there is still a need for more information to ascertain the relationship between instrumental and emotional support received by caregivers and their level of depression.
RESEARCH DESIGN AND METHOD

This descriptive study has a positivist orientation. It attempts to answer the question, "What instrumental and emotional supports do caregivers of SDAT patients who score with symptoms of depression receive and need?" The supports of caregivers (the independent variable) are correlated with the existence of or lack of symptoms of depression in caregivers (the dependent variable).

In answering the research question, this study tests four (4) hypotheses.

(H1) Caregivers of SDAT patients who receive higher scores on instrumental support from community resources have lower depression scores.

(H2) Caregivers of SDAT patients who receive higher scores on instrumental support from family/significant others have lower depression scores.

(H3) Caregivers of SDAT patients who rate higher satisfaction on emotional support from community resources have lower depression scores.

(H4) Caregivers of SDAT patients who rate higher satisfaction on emotional support from family/significant others have lower depression scores.

A convenience sample was taken from the ICRC client population of SDAT patient caregivers who live in San Bernardino County. The agency provided a list of all the
SDAT patient caregivers on their active caseload with each caregiver's depression score. This list contained 37 names. Letters (see Appendix B) were sent to these caregivers briefly describing the study and requesting participation. Follow-up phone calls were made to each of the 37 caregivers to obtain verbal consent of voluntary participation. Of the cases called, 19 agreed to participate (10 of which score with symptoms of depression and 9 who do not) and interviews were immediately scheduled.

Individual interviews were conducted by a single student researcher and lasted approximately forty five (45) minutes. Researchers strictly adhered to the format outlined in the attached questionnaire (See Appendix A) which consists of qualitative and quantitative questions. To test the hypotheses, caregivers were asked to rate the quality and quantity of the instrumental and emotional support they receive from community resources and from family/significant others. They were also asked to quote the number of instrumental support hours they receive.

There were many advantages to this interview format. Some caregivers were apprehensive that their participation would jeopardize their eligibility for services. Researchers were able to personally reassure caregivers of their continued eligibility for services regardless of the support they are currently receiving and regardless of their
participation in this research project. Thus, an honest atmosphere for obtaining accurate information was promoted.

Furthermore, researchers took steps to eliminate the potential for interviewer bias. They met and conferred before data collection began as well as throughout the interviewing process to ensure consistency of style and content.

After the interviews, the quantitative data from each of the 19 questionnaires was compiled and put into the computer forming a computer questionnaire and a data matrix. Univariate analysis (frequencies) were then run for each of the variables. Bivariate analysis (crosstabs) were computed to find the relationship independent variables and the dependent variable.

The qualitative data in this study was obtained in the latter portion of the interview when time was allotted for additional comments and ideas from caregivers. This data was analyzed by the method of open-coding. This involved writing each idea on a separate card and combining the cards with similar ideas into separate categories.

**HUMAN SUBJECTS**

For the protection of participants, informed consents (see Appendix C) were obtained from each person interviewed. Participants were also informed and assured that involvement
in the study would have no effect on their eligibility for services. The questionnaire (see Appendix A) utilized in each interview was assigned a different number so as to assure confidentiality of the participants. Only the researchers know what numbers are assigned to each participant. In addition, the researchers provided a debriefing statement (see Appendix D) with two contact phone numbers to call in the event of any questions or problems arising as a result of this study. One contact listed was David Fraser, LCSW, the program director involved in this study. The second contact listed was Dr. Marjorie Hunt, Ph.D., the University advisor for this project.

At the end of each interview, researchers debriefed participants by verbally giving a brief explanation of the steps that would follow in the research process. Interviewers informed participants of the completion date for this project and the availability of the final report at the agency after this date.

RESULTS

The independent variables in this study are the instrumental and emotional supports received from community resources and from family/significant others. The dependent variable is the depression scores of caregivers.
UNIVARIATE ANALYSIS

Caregiver Demographics

Radloff and Teri (1986) constructed a questionnaire to measure a person's current emotional state. They found that a score of 16 or above indicated symptoms of depression. Thus, for the convenience of statistical analysis, depression scores below 16 were combined to form the group of caregivers without symptoms of depression and the scores of 16 and above were combined to form the group of caregivers with symptoms of depression. As a result, 9 caregivers scored without symptoms of depression and 10 caregivers scored with symptoms of depression at the time of the interview.

Frequencies were then run for the demographic variables. Regarding gender, the sample consisted of 4 male and 15 female caregivers. Of these caregivers, age ranged from 37 to 84 years old. The mean age was 62.8 years but the mode age was 70 years. The most frequent ethnicity in this sample was Caucasian, 15 caregivers (78.9 percent). There were only 2 African-Americans, 1 Mexican-American, and 1 "Other" classification represented in this sample. There were no Asian/Pacific Islander or American Indian caregivers.
Of the 19 caregivers, 14 reported that they were married (73.7 percent). Four caregivers were divorced (21.1 percent) and 1 was separated. None of the caregivers were widowed or had never been married.

The annual household income variable was divided into 8 categories. The first category included all incomes of $10,000 or less a year. Each following category increased in increments of $5,000 to the last category of $40,000 or above. The mean annual household income was within the $25,000 to $29,999 a year range. The mode income was within the $15,000 to $19,999 a year range.

The most common employment status of the sampled caregivers was "not-employed". Fifteen caregivers reported inclusion in this category (78.9 percent) and for many, this meant retirement. There were no "full-time" employed caregivers, only 2 "part-time" employed caregivers, and 2 who report "other" as their employment status.

The caregiver relationship to the patient consisted primarily of spouses (52.6 percent), 6 wives (31.6 percent) and 4 husbands (21.1 percent). However, daughters made up the largest group of caregivers represented in this sample (36.8 percent). There were no caregiving sons or friends and only 2 "other family member" caregivers.

Caregivers were asked to rate their personal health on a 4-point scale of: excellent, good, fair, poor. The
majority (89.4 percent) of caregivers rated their health as good (52.6 percent) or fair (36.8 percent).

Patient Demographics

Demographic information was also collected on each patient. Of the 19 patients, 8 were male and 11 were female. The ages of these patients ranged from 69 to 94 years old and the mean age was 79.4 years. The patient ethnicity frequencies were identical to the caregiver ethnicity frequencies. There were 15 Caucasian patients, 2 African-American patients, 1 Mexican-American patient, and 1 "other" classification. Again, there were no Asian/Pacific Islander or American Indian patients in this sample.

Of the 19 patients, 12 were married (63.2 percent), 6 were widowed (31.6), and 1 was separated (5.3 percent).

Caregivers were asked to estimate the length of patient impairment. This ranged from 1 to 21 years with a mean of 7.4 years. The majority of caregivers reported a length of impairment between 5 to 10 years (52.6 percent).

Instrumental Support

The last two pages of the questionnaire addressed the instrumental and emotional support received by caregivers from both community resources and from family/significant others resources. Caregivers were first asked the average hours of instrumental support they receive each week from community resources. They reported a range from zero hours...
to 97 hours a week. The most common answer was zero hours a week (36.8 percent) while the rest predominantly fell within the range of 4 to 24 hours a week (57.9 percent). One caregiver reported receiving 97 hours of community instrumental support each week and so the mean score is not a good indication of the actual average hours of support.

Secondly, caregivers were asked the average hours of instrumental support they receive each week from family/significant others resources. They reported a range from zero hours to 49 hours each week. Again, the most common answer was zero hours a week (42.1 percent) and 15 out of the 19 caregivers (78.9 percent) reported 6 or less hours of family/significant others instrumental support each week.

Finally, the total number of instrumental support hours were figured for each case (combination of both community and family/significant others resources). The totals ranged from zero hours to 99 hours each week and the mean was 20.9. Of the 19 caregivers, 31.6 percent reported receiving 6 hours or less each week and there was a fairly even distribution between 9.5 hours and 35.5 hours for 57.9 percent of the caregivers. Beyond this, 2 caregivers reported much higher totals of 49 hours each week and 99 hours each week.
Caregivers were asked to rate the quantity and quality of instrumental and emotional support that they receive from community resources and family/significant others resources (see Appendix A). Those who did not receive any instrumental or emotional support were not asked to rate the quality of the nonexistent support (and thus were assigned as missing data), but were asked to rate their feelings regarding the quantity.

The majority of caregivers (52.6 percent) rated the quantity of community instrumental support as "far less" than needed. Four caregivers (21.1 percent) reported that the support was "Somewhat less" than they needed and only 5 caregivers (26.3 percent) reported that the quantity of this support was "about what they needed." Thus, 73.7 percent of caregivers reported dissatisfaction with the quantity of community instrumental support that they are receiving. None of the caregivers reported this support as being "more than" they needed or as "not needed."

Of those who did receive community instrumental support, 92.3 percent rated the quality of this support as "excellent" (53.8 percent) or "good" (38.5 percent). Only 1 caregiver rated this support as "fair" and there were no ratings of "poor" for this support. There were 6 "missing data" of caregivers who did not receive this support at all and therefore did not participate in this rating.
In the family/significant others instrumental support category, 57.9 percent of the caregivers rated the quantity of this support as "far less" (26.3 percent) or "somewhat less" (31.6 percent) than they need. The mode rating (36.8 percent) was that this support is "about what they need." One caregiver reported that this support was more than they needed.

Of those who received instrumental support from family/significant others resources, 72.7 percent rated the quality of this support as "excellent" (27.3 percent) or "good" (45.5 percent). Two caregivers rated this support as "fair" (18.2 percent) and one caregiver rated it as "poor" (9.1 percent). There were 8 "missing data" in this category.

Emotional Support

In the community emotional support category, 57.9 percent rated the quantity of this support as "far less" (15.8 percent) or "somewhat less" (42.1 percent) than they need. Seven caregivers rated the quantity of this support as "about what they need" (36.8 percent) and one caregiver rated that they "do not need" this support. No caregivers rated that this support was "more than" they needed.

Of those who received community emotional support, 84.6 percent rated the quality this support as "excellent" (53.8 percent) or "good" (30.8 percent). One caregiver rated this
support as "fair" and one rated it as "poor." There were 6 "missing data" in this category.

In the family/significant others emotional support category, 42.1 percent rated the quantity of this support as "far less" (26.3 percent) or "somewhat less" (15.8 percent) than they need. However, the majority of caregivers rated this support as "about what they need" (57.9 percent). No caregivers reported that they "did not need" this support or that it was "more than they needed."

Of those who received family/significant others emotional support, 84.2 percent rated the quality of this support as "excellent" (31.6 percent) or "good" (52.6 percent). Two caregivers rated this support as "fair" (10.5 percent) and one rated it as "poor." There were no "missing data" in this category, which means that all the caregivers in this sample received some amount of emotional support from family/significant others resources.

**BIVARIATE ANALYSIS**

Crosstabs (bivariate analysis) were carried out to assess the significance of the relationship between the independent variables and the dependent variables. There was a fairly even distribution in the dependent variables of
those scoring with symptoms of depression (10) and those who did not score with symptoms of depression (9).

**Instrumental Support**

In the category of community instrumental support, 60 percent of the caregivers scoring with symptoms of depression rated the quantity of this support as "far less" (30 percent) or "somewhat less" (30 percent) than they need. The remaining 40 percent rated the quantity as "about what they need." For those not scoring with symptoms of depression, 89 percent rated the quantity of this support as "far less" (78 percent) or "somewhat less" (11 percent) than they need, while the remaining 11 percent felt it was "about what they need." None of these caregivers, reported the quantity of this support as "more than needed" or "not needed."

The quality of community instrumental support was rated by 88 percent of the caregivers scoring with symptoms of depression as "excellent" (50 percent) or "good" (38 percent), while 100 percent of those not scoring with symptoms of depression rated the quality as "excellent" (60 percent) or "good" (40 percent). Only 12 percent of those with symptoms of depression scored the quality as "fair."

There were six missing data in this crosstabulation due to their response of not receiving any community instrumental
support (2 from those scoring with symptoms of depression and 4 from those without).

In the category of family/significant others instrumental support, 40 percent of caregivers scoring with symptoms of depression rated the quantity of this support as "far less" (20 percent) or "somewhat less" (20 percent) than needed. Whereas, 60 percent of these caregivers rated the quantity of this support as "about what they need." For those not scoring with symptoms of depression, 78 percent rated the quantity of this support as "far less" (33 percent) or "somewhat less" (45 percent) than needed. Eleven percent rated quantity as "about what they need" and the remaining 11 percent rated "more than needed."

The quality of family/significant others instrumental support was rated by 80 percent of caregivers scoring with symptoms of depression as "excellent" (40 percent) or "good" (40 percent), while only 20 percent rated "fair." For those not scoring with symptoms of depression, 67 percent rated quality as "excellent" (17 percent) or "good" (50 percent). The remaining third (33 percent) of the caregivers were divided equally in rating this support as "fair" or "poor." There were 8 missing data in this category (5 from those scoring with symptoms of depression and 3 from those without).
Emotional Support

In the category of community emotional support, 50 percent of caregivers scoring with symptoms of depression rated the quantity as "far less" (20 percent) or "somewhat less" (30 percent) than needed, while 50 percent rated the quantity as "about what they need." Of those who did not score with symptoms of depression, 67 percent rated the quantity of this support as "far less" (11 percent) or "somewhat less" (56 percent) than needed. Twenty two percent rated it as "about what they need" and 11 percent rated the support as "not needed."

The quality of community emotional support was rated by 75 percent of caregivers scoring with symptoms of depression as "excellent" (50 percent) or "good" (25 percent). The remaining 25 percent were divided equally in rating this support as "fair" or "poor." Of those not scoring with symptoms of depression, 100 percent rated the quality of this support as "excellent" (60 percent) or "good" (40 percent). There were 6 missing data in this category (2 from those scoring with symptoms of depression and 4 from those without).

In the category of family/significant others emotional support, 50 percent of caregivers scoring with symptoms of depression rated the quantity of this support as "far less" (30 percent) or "somewhat less" (20 percent),
while 50 percent rated it as "about what they need." Of those caregivers not scoring with symptoms of depression, 33 percent rated this quantity as "far less" (22 percent) or "somewhat less" (11 percent), while 67 percent rated it as "about what they need."

The quality of the family/significant others emotional support was rated by 80 percent of caregivers scoring with symptoms of depression as "excellent" (40 percent) or "good" (40 percent). The remaining 20 percent were divided equally in rating this support as "fair" or "poor." Of those caregivers not scoring with symptoms of depressions, 89 percent rated the quality of this support as "excellent" (22 percent) or "good" (67 percent), with only 11 percent rating this support "fair." There were no missing data in this category, which indicates that all caregivers in this sample are receiving some amount of emotional support from family/significant others.

In terms of the qualitative data, comments seemed to only duplicate and support the quantitative data. For example, many caregivers commented on their deep need for some form of respite assistance on a daily, weekly, or "as needed" basis. This replicated the data gained in the quantitative piece regarding instrumental support hours received. The most common answer was zero hours received each week from community support (36.8 percent) and from
family/significant others (42.1 percent). Caregivers expressed dissatisfaction with this lack of support from community resources (73.7 percent) and from family/significant others (57.9 percent) by rating it as "far less" or "somewhat less" than they need.

Summary

In testing the first hypothesis, the majority of caregivers with lower depression scores (not scoring with symptoms of depression) voiced dissatisfaction with the quantity of community instrumental support, but unanimously gave high ratings to the quality of the support they were receiving. The majority of caregivers with higher depression scores (those scoring with symptoms of depression) voiced dissatisfaction with the quantity of this support but gave high ratings to the quality of this support (see Table 1).

For the second hypothesis, the majority of caregivers with lower depression scores again voiced dissatisfaction with the quantity of instrumental support from family/significant others, but highly rated the quality of the support they were receiving. The majority of caregivers with higher depression scores voiced satisfaction with the quantity of this support and gave high scores to the quality (see Table 2).
In testing the third hypothesis, the majority of caregivers with lower depression scores voiced dissatisfaction with the quantity of emotional support from community resources, but unanimously gave high ratings to the quality of the support they are receiving. Caregivers with higher depression scores were evenly divided in voicing satisfaction and dissatisfaction with the quantity of this support, but the majority gave high ratings to the quality (see Table 3).

Finally, in testing the fourth hypothesis, the majority of caregivers with lower depression scores voiced satisfaction with the quantity of emotional support from family/significant others and gave high ratings to the quality of the support they are receiving. Caregivers with higher depression scores again were evenly divided in voicing satisfaction and dissatisfaction with the quantity of this support, but the majority gave high ratings to the quality (see Table 4).
TABLE 1 — Instrumental Community Support

<table>
<thead>
<tr>
<th>Quantity</th>
<th>Far less than need</th>
<th>Somewhat less than need</th>
<th>About what is needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms of Depression</td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 78 %</td>
<td>3 30 %</td>
<td>10 52.6 %</td>
</tr>
<tr>
<td></td>
<td>1 11 %</td>
<td>4 30 %</td>
<td>4 21.1 %</td>
</tr>
<tr>
<td></td>
<td>1 11 %</td>
<td>4 30 %</td>
<td>5 26.3 %</td>
</tr>
<tr>
<td></td>
<td>9 47.4 %</td>
<td>10 52.6 %</td>
<td>19 100 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0 missing cases</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality</th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms of Depression</td>
<td>No</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 60 %</td>
<td>4 50 %</td>
<td>8 53.8 %</td>
</tr>
<tr>
<td></td>
<td>2 40 %</td>
<td>3 38.5 %</td>
<td>5 38.5 %</td>
</tr>
<tr>
<td></td>
<td>0 0 %</td>
<td>1 12 %</td>
<td>1 7.7 %</td>
</tr>
<tr>
<td></td>
<td>5 38.5 %</td>
<td></td>
<td>13 100 %</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6 missing cases</td>
</tr>
</tbody>
</table>

27
TABLE 2 — Instrumental Family/Significant Others Support

Quantity

<table>
<thead>
<tr>
<th>Symptoms of Depression</th>
<th>Far less than needed</th>
<th>Somewhat less than needed</th>
<th>About what is needed</th>
<th>More than needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
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<td></td>
<td>33 %</td>
<td>45 %</td>
<td>11 %</td>
<td>11 %</td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
<td>2</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>20 %</td>
<td>20 %</td>
<td>60 %</td>
<td>0 %</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>26.3 %</td>
<td>31.6 %</td>
<td>36.8 %</td>
<td>5.3 %</td>
</tr>
</tbody>
</table>

0 missing cases

Quality

<table>
<thead>
<tr>
<th>Symptoms of Depression</th>
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<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>17 %</td>
<td>50 %</td>
<td>16.5 %</td>
<td>16.5 %</td>
</tr>
<tr>
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<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>40 %</td>
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<td>0 %</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>27.3 %</td>
<td>45.5 %</td>
<td>18.2 %</td>
<td>9.1 %</td>
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</table>
TABLE 3 -- Emotional Community Support

<table>
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<th>Somewhat less than needed</th>
<th>About what is needed</th>
<th>Do Not Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>1 11 %</td>
<td>5 56 %</td>
<td>2 22 %</td>
<td>1 11 %</td>
</tr>
<tr>
<td>Yes</td>
<td>2 20 %</td>
<td>3 30 %</td>
<td>5 50 %</td>
<td>0 0 %</td>
</tr>
<tr>
<td></td>
<td>3 15.8 %</td>
<td>8 42.1 %</td>
<td>7 36.8 %</td>
<td>1 5.3 %</td>
</tr>
</tbody>
</table>

0 missing cases

<table>
<thead>
<tr>
<th>Symptoms of Depression</th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>3 60 %</td>
<td>2 40 %</td>
<td>0 0 %</td>
<td>0 0 %</td>
</tr>
<tr>
<td>Yes</td>
<td>4 50 %</td>
<td>2 25 %</td>
<td>1 12.5 %</td>
<td>1 12.5 %</td>
</tr>
<tr>
<td></td>
<td>7 53.8 %</td>
<td>4 30.8 %</td>
<td>1 7.7 %</td>
<td>1 7.7 %</td>
</tr>
</tbody>
</table>

6 missing cases
**TABLE 4 — Emotional Family/Significant Others Support**

### Quantity

<table>
<thead>
<tr>
<th>Symptoms of Depression</th>
<th>Far less than need</th>
<th>Somewhat less than need</th>
<th>About what is needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>22 %</td>
<td>11 %</td>
<td>67 %</td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>30 %</td>
<td>20 %</td>
<td>50 %</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>26.3 %</td>
<td>15.8 %</td>
<td>57.9 %</td>
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0 missing cases

### Quality

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<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>22 %</td>
<td>67 %</td>
<td>11 %</td>
<td>0 %</td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>4</td>
<td>1</td>
<td>1</td>
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<td></td>
<td>40 %</td>
<td>40 %</td>
<td>10 %</td>
<td>10 %</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>10</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>31.6 %</td>
<td>52.6 %</td>
<td>10.5 %</td>
<td>5.3 %</td>
</tr>
</tbody>
</table>

0 missing cases

30
DISCUSSION

This positivist descriptive study addressed the question "What instrumental and emotional supports do caregivers of Senile Dementia/Alzheimer Type (SDAT) patients who score with symptoms of depression receive and need?" The four hypothesis proposed that the higher caregivers rate (quantity and quality) instrumental and emotional support received from community and family/significant others resources, the lower their depression scores.

The findings of this study replicate the findings of previous research regarding women being primary caregivers and daughters in particular (Miller, 1981). This also strongly suggests that the population sample in this study is representative of this particular population in terms of caregiver composition.

In regard to instrumental support, the results indicate that the majority of caregivers with lower depression scores voice dissatisfaction with the quantity of both community and family/significant others support. This appears to contradict hypotheses 1 and 2. However, the subjects gave predominantly high ratings regarding the quality of this support. Thus, these results indicate that although the quantity of instrumental support is less than caregivers
need, they are highly satisfied with the quality of the support they are receiving.

For those caregivers with higher depression scores, the significant difference is that the majority voiced satisfaction with the quantity and quality of instrumental support from family/significant others.

Ultimately, all caregivers, regardless of their depression score, voiced dissatisfaction with the quantity of support they are receiving from community resources. This is strongly supported by the qualitative data. An overwhelming number of caregivers commented on their need for additional community supports in the form of respite, support groups, senior companions, church support and involvement, legal and financial assistance, and additional social work services.

The implications for treatment are that caregivers indicate a need for more community services, not improved services. Further research should inquire as to specific services needed, and the prioritization of these services.

In regard to emotional support, caregivers demonstrate mixed feelings over the quantity of support received. The majority of those with low depression scores indicate dissatisfaction with the quantity of emotional support received from the community, but most indicated satisfaction with the quantity received from family/significant others.
The majority of caregivers with high depression scores were equally divided in their satisfaction and dissatisfaction regarding the quantity of emotional support received from community resources as well as from family/significant others. All caregivers gave high quality ratings to the emotional support received, regardless of its source or their depression score. It is impossible to draw any firm conclusions as to hypothesis 3 and 4 with these results. Their inconclusiveness indicates that caregivers may experience levels of depression ranging from mild, moderate, to severe. This implies a need for further research exploring emotional support needed in all levels of depression, not just the two levels of those scoring with depression and those without. These results also indicate a complexity of the emotional needs that caregivers experience, hence the difficulty in quantitatively rating emotional support.

In the qualitative data, caregivers identified key emotions that they were feeling as a result of their caregiving role. Depression, anger, and anxiety were the predominant emotions expressed. They struggled with feelings of hopelessness, sadness, and frustration related to patient care and their perceived personal losses as a result of this responsibility. Many presented somatic complaints such as physical pain, heart palpitations, back
pain, headaches, insomnia, etc. for which many were taking prescribed medications. These findings support the above conclusion that the complexity of caregiver emotional needs is such that it is not only difficult to evaluate, but difficult to establish and deliver appropriate services. In order to meet the emotional needs of caregivers, further research must address the complexity of this issue.
QUESTIONNAIRE

Appendix A

ID # ____________ Interview Date: ____________

CAREGIVER INFORMATION

Gender ____ DOB _____________ Age ______________

Ethnicity: ____________________________ Marital Status: ____________________________
____ Caucasian ________________________ Married ____________________________
____ African American __________________ Divorced ____________________________
____ Mexican American __________________ Separated ____________________________
____ American Indian __________________ Widowed ____________________________
____ Asian/Pacific Islander _____________ Never Married _______________________
____ Other ____________________________ Other ____________________________

Annual Household Income: ____________________________ Employment Status: ____________________________
____ Under ________ $9,999 ________________________ Full-time ____________________________
____ $10,000 ________ $14,999 ______________________ Part-time ____________________________
____ $15,000 ________ $19,999 ______________________ Not employed ____________________________
____ $20,000 ________ $24,999 ______________________ Other ____________________________
____ $25,000 ________ $29,999 ______________________
____ $30,000 ________ $34,999 ______________________
____ $35,000 ________ $39,999 ______________________
____ $40,000 ________ above _______________________

Relationship to Patient: ________________

Rate Current Personal Health: ____________________________
____ Excellent ________________
____ Good ________________
____ Fair ________________
____ Poor ________________

PATIENT INFORMATION

Gender ____ DOB _____________ Age ____

Ethnicity: ____________________________ Marital Status: ____________________________
____ Caucasian ________________________ Married ____________________________
____ African American __________________ Divorced ____________________________
____ Mexican American __________________ Separated ____________________________
____ American Indian __________________ Widowed ____________________________
____ Asian/Pacific Islander _____________ Never Married _______________________
____ Other ____________________________ Other ____________________________

Length of patient impairment: ____________________________
A. Actual number of hours the caregiver receives instrumental assistance in caring for the patient each week:

Rate Quantity of instrumental help: Rate Quality of instrumental help:

| 1 | Far less than you need | 1 | Excellent |
| 2 | Somewhat less than you need | 2 | Good |
| 3 | About what you need | 3 | Fair |
| 4 | More than you need | 4 | Poor |
| 5 | You don't need emotional help |

<table>
<thead>
<tr>
<th>From Whom:</th>
<th>How Many Hours:</th>
<th>Quantity</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daycare</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Health Aide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Board and Care Facility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled Nursing Facility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

COMMENTS: ________________________________

36
Rate Quantity of emotional help:  
Rate Quality of emotional help:

1. Far less than you need
2. Somewhat less than you need
3. About what you need
4. More than you need
5. You don't need emotional help

<table>
<thead>
<tr>
<th>From Whom:</th>
<th>Quantity</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daycare</td>
<td></td>
<td></td>
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<tr>
<td>Home Health Aide</td>
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<td></td>
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<tr>
<td>Nurse</td>
<td></td>
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<tr>
<td>Board and Care Facility</td>
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<tr>
<td>Skilled Nursing Facility</td>
<td></td>
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</tr>
<tr>
<td>Church</td>
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</tr>
<tr>
<td>Support Group</td>
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</tr>
</tbody>
</table>

COMMENTS: ____________________________

____________________________

____________________________

____________________________

____________________________

____________________________

____________________________

____________________________

____________________________

37
Appendix B

PARTICIPATION REQUEST

December 28, 1992

Dear Caregiver,

We are writing to request your participation in a research project that will study the emotional and instrumental experiences of caregivers of Senile Dementia/Alzheimer's Type patients. This project will be conducted in conjunction with the Social Work Department at California State University, San Bernardino. Your participation in this study would be completely voluntary and would have no effect on the services you are currently receiving or the services that you may receive in the future from Inland Caregiver Resource Center. It is our hope that the results of this study will aide in future program development and services at the center.

Participation in this project would involve one 30-45 minute interview. This interview will consist of questions regarding the types of instrumental and emotional support that you are currently receiving as well as the types of support that you still need.

We will be calling you within the next two weeks for your answer to this request.

Sincerely,

Social Work Research Team

Lisa Hilder, Social Work Intern

Kerri Robertson, Social Work Intern

___________________________________________________________________________

38
CONSENT FORM

I consent to participate in the research project entitled "The Emotional and Practical Experiences of Senile Dementia/Alzheimer Type (SDAT) Patient Caregivers." The purpose of this project is to explore the instrumental and emotional support received and needed by SDAT patient caregivers as well as their symptoms and level of emotional experience. The research procedure will involve one 30-45 minute interview by one of the two social work interns conducting the study. This study of Inland Caregiver Resource Center (ICRC) caregivers will be done in conjunction with the Master's of Social Work Department at California State University, San Bernardino (CSUSB). I understand that my participation in this project will have no affect on the services I am currently receiving or the services that I may receive in the future from ICRC.

I understand that my participation is voluntary and that all information is confidential and that my identity will not be revealed. I am free to withdraw consent and to discontinue participation in the project at any time. Any questions about the project will be answered by the researcher named below or by a representative from ICRC or the Master's of Social Work Department at CSUSB. CSUSB and the researcher named below have responsibility for insuring that participants in research projects conducted under university auspices are safeguarded from injury or harm resulting from such participation.

On the basis of the above statements, I agree to participate in the project.

__________________________________________  __________________________
Participant's Signature  Researcher's Signature

__________________________________________  __________________________
Date  Date
DEBRIEFING STATEMENT

If any questions or concerns arise as a result of this project interview, the individuals named below may be contacted for assistance. In addition, the results of this study will be available in the library at Inland Caregiver Resource Center as well as California State University, San Bernardino by June of 1993. Thank you very much for your participation in this research project.

Social Work Research Team
Lisa Hilder, Kerri Robertson
Social Work Interns

Inland Caregiver Resource Center Contact Representative:
David Fraser, MSW
Program Director
Phone #714-387-9440

Master's of Social Work Department, California State University, San Bernardino Contact Representative:
Dr. Marjorie Hunt
Professor of Social Work
Phone #714-880-5501
REFERENCES


